

"Not Just a Wheelchair, Not Just a Woman": Self-Identity and Leisure

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This study was conducted to address the lack of information available about leisure and the self-identity of women with physical and sensory disabilities. The purpose of this analysis was to explore how self-identity and leisure were related. Symbolic interactionism was the theoretical framework used to analyze how gender and disability influenced leisure behavior. In-depth interviews were undertaken with 30 adult women who were functioning independently in their communities. Themes that emerged from the interviews related to how the women with disabilities perceived their leisure and self-identity. Self-identity, as related to leisure attitudes and behavior, was influenced by the overlapping aspects of self-perception, body identity, gender identity, and role identity. Implications for the delivery of leisure services are discussed regarding these themes.

KEY WORDS: *women, physical disabilities, leisure, self-identity, role-identity, gender-identity*

"Not just a Wheelchair, Not just a Woman": Self-Identity and Leisure
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are not a person, you are a wheelchair. I love to dress up, put on make-up, the whole thing. It gives me self-confidence, makes me feel better as a

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Thanks are extended to Karen Luken of the Center for Recreation and Disability Study in the Curriculum in Leisure Studies and Recreation Administration (UNC-CH) for her initial review of this article and to Rosemary Schuler, graduate assistant, who assisted in data collection. This paper was presented at the American Therapeutic Recreation Association (ATRA) Research Institute in September 1993 in Towson, Maryland.

person. (Words of a 29-year old African-American married mother who is paraplegic and uses a wheelchair.)

Women who have disabilities often are considered by society to have a "double handicap" (Deegan & Brooks, 1985, p. 6) or to be a multiple minority. Women with disabilities are women first, sharing the dreams and disappointments common to most women in a male-dominated society (Fine & Asch, 1988). Because of their disabilities, however, they may view the world differently than women without disabilities.

The significance of a disability is affected by a person's feeling about the self and the situation (Wright, 1983). A disability may have an adverse impact when it disrupts a woman's actual or perceived abilities to perform important self-defining activities and roles. A sense of rolelessness and lack of positive self-identity, mitigated by gender and a disability, may affect leisure behaviors of some women with disabilities. Further, it appears that the self-identity of a woman may influence her attitude toward and involvement in leisure as well. For purposes of this study, the definition of self-identity that evolved from the data included a woman's attitude about herself in relation to self-perception, body-identity, gender-identity, and role-identity.

The purpose of this analysis was to explore how self-identity and the leisure of women with physical and sensory disabilities were related. Women with disabilities who functioned independently in the community were chosen for study because they are a group that generally has been under-researched in the leisure literature (Traustadottir, 1992). Feminists, as well as other researchers, are now recognizing the value of acknowledging and examining the diverse experiences of women. Although one cannot generalize about women from any one group of experiences (Brown, 1990), when "women and leisure" are discussed, the ex-

periences of women with disabilities must not become invisible.

Studying women with disabilities in the United States is important because over half of the people with disabilities in the United States are female and 16% of females have a disability (Wendell, 1989). In general, these women receive less from public income support programs than do men with disabilities, despite their often greater economic need (Mudrick, 1988). This difference is due to the typical work roles and the structures of family roles. Further, the statistics for divorce among women with disabilities is higher than for men with disabilities (Cole, 1988). Thus, it appears that one's gender, defined as a socially constructed set of expectations based upon one's biological sex, may require examination if the meanings of leisure for women with disabilities are to be further understood. Examining the self-identity of women with disabilities may help to understand their experiences in leisure and how the quality of life for all people might be enhanced through leisure.

Theoretical Framework and Related Literature

An interpretive paradigm was the basis for the study. In-depth qualitative interviews were used to encourage women with physical, including sensory, disabilities to talk about their lives, their identity, and the meanings of leisure. Symbolic interactionism provided the framework for conducting this study.

Symbolic interactionism provided a theoretical and epistemological way to understand leisure and women with physical disabilities. According to Blumer (1969), symbolic interactionism assumes that human beings are conscious, feeling, thinking, and reflective subjects. Human behavior is not static but dynamic and occurs in a fluid and every-changing context of social interaction. People impute meanings about what is

happening around them and how they are interacting with others. Thus, symbolic interactionism is concerned with understanding the concept of self in relation to the definition of a situation. This study addressed the relationship that some women with physical disabilities had to leisure. According to Samdahl (1987), using symbolic interactionism can enable leisure researchers and leisure practitioners to see how leisure is perceived as a distinctive pattern related to ongoing interactions. The researchers sought to understand how the combination of gender, self-identity, and disability resulted in varying forces that influenced leisure attitudes and behavior for women with physical disabilities.

Methods

Traditional quantitative approaches often have been unable to uncover the complex nature of women's attitudes and practices (Lenskyj, 1989), let alone the additional experience of disability. The qualitative approach allows researchers to seek understanding and to identify patterns through an exploration of specific cases (cf. Howe, 1993; McCormick, 1991; Whitson & Macintosh, 1989). The leisure of women with physical disabilities was explored using indepth qualitative interviews. The questions were designed to encourage the women to talk about their lives and to provide the researchers with insights about how women defined themselves as female and as having a disability (Wendell, 1989).

Interviews included a two stage process. Respondents were initially invited to participate in a 45-120 minute interview at a convenient location with a trained interviewer. The questions asked followed an interview guide format (Henderson, 1991) with appropriate probes used to encourage an informal conversation. The interviews were tape-recorded and transcribed. Participants were given an opportunity to review the tran-

scripts and make any corrections or additions to the interview. A second stage interview which lasted 45-90 minutes was conducted with six of the original interviewees to "check" the emerging interpretations of the data. In addition to the transcriptions of each interview, notes from the interviews and weekly meetings of the researchers over two semesters were recorded as data.

The first stage interview guide included questions such as: Explain the nature of your disability; what do you like to do for fun; how has recreation changed over the course of your life; how would leisure be different if you did not have a disability; what prevents you from doing all the things you'd really like to do; describe a typical weekday for you; describe a typical weekend; what are some of the things that you look forward to in life; what are some of the things that concern you about the future. The second stage of the interviews included a discussion with individual interviewees concerning the themes of self-identity that had emerged in conducting the first interview. The respondents were asked to provide feedback to the researchers' initial conclusions and to offer examples of how they agreed or disagreed with the emerging themes as related to their own leisure lives. The data presented in this paper represent one small piece of the data analysis that is ongoing in this research project.

Data analyses were conducted using the constant comparison technique (Glaser & Strauss, 1967) which is a systematic method for recording, coding, and analyzing qualitative data. The purpose of constant comparison is to maximize credibility through comparison of groups and data. This method was used by the three researchers individually, and then as a group, to come eventually to consensus concerning the coding and interpretation of the data. Constant comparison involved the procedure of reading all transcripts to develop a broad understanding of the content. The data were coded to

reflect major themes, and then recoded into subthemes to reflect specific content. Finally, the researchers re-examined the data to ascertain that the categories fit the data and vice versa. Analytic induction was applied post hoc to enable the researchers to interpret the grounded theory related to the themes generated.

The "trustworthiness" (Henderson, 1991; Lincoln & Guba, 1985) of the interpretation was determined by examining the credibility, transferability, dependability, and confirmability of the results. Corroboration and triangulation among the researchers were used to develop credibility and dependability. As the data were collected, the guiding hypotheses changed as the types of information uncovered became more defined. Member checks were conducted in the second stage of the procedure to ensure that the interpretations were confirmable and accurate. Examples were used throughout the analysis to indicate how the researchers arrived at their conclusions based on the words of the interviewees.

Respondents

A theoretical sampling technique was used to interview 30 women during the spring of 1992. Theoretical sampling is used in the qualitative approach to collect data with the purpose of reaching theoretical saturation, or the point at which no new data themes appear to emerge (Henderson, 1991).

The women in this study represented a variety of sensory and physical disabilities, married and single, African-American and European-American, with and without children, a variety of age groups, and working inside and outside the home. Initial informants were obtained through researcher contacts with recreation and other human service professionals in a quasi-metropolitan area in the southeast United States. Additional informants were solicited from the initial interviewees. The women included in

the study were those individuals who described themselves as individuals with physical or sensory disabilities. All individuals were living independently in the community.

The average age of the thirty interviewees was 40 years-old with a range of 25-57 years. Nine of the women were African-American and the remainder ($n = 21$) were European-American. Slightly over half ($n = 16$) of the interviewees were single or divorced and less than half ($n = 14$) were married. Sixteen of the women had children. The age ranges of the children were from in utero to 34 years old. The group was educated with all possessing at least a high school education and the average being three years of training/education beyond high school. Slightly over half ($n = 16$) of the women were employed ($n = 9$ as professionals and $n = 7$ in service positions) with the remainder being homemakers ($n = 8$), students ($n = 3$), or unemployed ($n = 3$). Six of the women had a disability all their lives. The remaining 24 women had a disability for an average of 19 years with a range of two years to 45 years. The following disabilities were represented: visual impairment ($n = 5$), rheumatoid arthritis ($n = 3$), multiple sclerosis ($n = 3$), spinal cord injury ($n = 3$), chronic fatigue syndrome ($n = 3$), hearing impairment ($n = 2$), cerebral palsy ($n = 2$) and other ($n = 9$; overweight, hypertension, cystic fibrosis, Ehlers-Danlos syndrome, muscular problems, Charcot-Marie-Tooth syndrome, stroke, post polio, osteogenesis imperfecta).

Self-Identity and Leisure

Wearing (1991) suggested that class, ethnicity, age, and gender are shown to structure leisure, and presumably leisure identity. She further suggested that leisure enables one to construct identities that may resist traditional male definitions and make way for individuality in leisure experiences for women. The purpose of this analysis was

to explore the self-identity and leisure of a group of women with physical disabilities to see how identities, which emerged as self-perception, body-identity, gender-identity, and role-identity influenced leisure.

Before addressing the relationship of identities to leisure for women with physical disabilities, it may be useful to explore how the women interviewed defined leisure and its meanings in their lives. Most of the women described leisure as free time or having time to do the things they wanted to do. They also talked about "having fun," "relaxing," "doing nothing," or "doing things at your own will and pace." A general distinction was made between recreation and leisure as was indicated by this 41-year old married woman with chronic fatigue syndrome:

To me, recreation is, ah, doing something physical. Playing softball with your child or riding a bike or something along that line. And leisure can be just doing something quietly like reading a book or even playing a game, but something that's quiet. So to me that's the difference.

Among the examples of leisure and recreation activities that the women with disabilities said they enjoyed doing were: dancing, eating out, shopping, painting pictures, writing poetry, planting flowers, listening to music, sewing, swimming, photography, birdwatching, walking, church activities, watching TV, playing games. No single activity or even group of activities was more common for women with disabilities than for other women. While the data do not allow a direct comparison with women without disabilities, the descriptions of activities resulted in a pattern similar to that found in other studies where women have been interviewed about their activities (cf. Deem, 1986; Green, Hebron, & Woodward, 1990; Henderson, 1990; Henderson & Bialeschki, 1991). Overall, the data suggested that soli-

tary and more passive activities were done in the home while going into public to participate in a more active recreation often required some type of assistance or companionship if it was to be successfully negotiated.

Most of the women with physical disabilities realized that they had some limitations in their lives, and thus their leisure. One woman with osteogenesis imperfecta stated, "I just have to do things differently but I don't see my [leisure] needs as being different." A woman with multiple sclerosis indicated that her leisure would not be different if she did not have a disability but she explained:

It would be easier and less frustrating. I wouldn't have to modify everything. Everything I do is slow paced and I'm very impatient with myself—more impatient with myself than with other people . . . I'd be more independent than I am. That's the biggest thing, you lose your independence.

Foundations of Self-Identity

The definition of self-identity that emerged from in this data analysis related to how an individual woman with a disability felt about herself relative to her particular circumstances. Further, the women suggested that their self-identity was frequently bound in social norms and social stigmas. Some of the problem with dysfunction due to disability was rooted in the perceived attitudes, stereotypes, and prejudices held by others, that sometimes limited the opportunities to participate in usual life roles and leisure behaviors. How the women with physical disabilities conformed to verses resisted the expectations surrounding their situations had implications for understanding the leisure of women without disabilities (cf. Freysinger & Flannery, 1992; Wearing, 1991) as well as women with physical disabili-

ities. Four overlapping aspects of identity that had a relationship to leisure emerged from the data: self-perception, body-identity, gender-identity, and role-identity. These aspects could be analyzed for any woman and her leisure, but due to the circumstances of their lives, women with physical disabilities sometimes viewed themselves from different perspectives.

Self-Perception. Self-perception included those beliefs, values, and expectations that provided the definition of self and what one was capable of doing. Self-esteem, referring to the general evaluation of self as a worthy or unworthy person (Wright, 1983) and self-efficacy as an individual's perception of the ability to perform anticipated demands required of daily living (Bandura, 1977) were analyzed as components of self-perception.

Self-perception also was determined by both personal views and the views of others. In addition, a woman's self-perception often was influenced by her perception of her abilities and disabilities. Some of the women with physical disabilities who were interviewed talked very little about their disabilities while others seemed to define themselves by their disability. For example, the first recorded question asked of the interviewees after preliminary introductions were made was "tell me something about you." While this question may have been biased by the fact that the interviewees had been told the study was about women with disabilities and leisure, many of the interviewees told the researchers something about themselves like their job, their family, or recreation interests while some talked about their disability first. Thus, self-perception as defined by the disability seemed to vary greatly among the women.

Some women clearly felt a negative identity because of the disability. A woman with paraplegia noted the negative effects from others: "It's bad enough, it's just like when you're in a wheelchair, period, you're stripped of your personality or your being. . . ." One mother with cystic fibrosis ex-

plained how she overcame the perception she had had since childhood that she could not exert herself:

I wanted to exercise, I wanted to take care of myself. And I, I really wanted to jog. But, I had this mental block that said, that told me that I couldn't do this. . . . And I just decided one day I was going to go out and try. And I jogged around one block and I said, this is not hard at all and I did it and I didn't keel over. . . . They've told me all these years I can't do this. And then I started and I did this every day. . . . I didn't run fast and I didn't run 5 miles or anything, but I did this and it was something I did every day after work . . . and I was very proud of myself.

Some women, in fact, seemed to get a positive identity from their disability (Asch & Fine, 1988). One single forty year old professional woman who has had arthritis since the age of eleven remarked, "I am the disability." She later stated:

I think that although it wouldn't have been my choice, there are sides of life that I see because I have arthritis. I wouldn't be the person I am today if I didn't have arthritis. . . . there's probably nobody who would give up what they have for what I am able to see, but I'm sure glad that I have the vision that I have.

Another woman described how when people have a disability, they tend to develop "something extra to make up for their disability." She went on to suggest that, "I think maybe they give it the wrong name, disability. And maybe they should give it the art of ability."

These statements reflected some of what Weinberg (1988) found in that some people

embraced their disabilities and viewed them as a challenge. Being able to cope or adapt increased their confidence and satisfaction. One 42 year old woman with multiple sclerosis noted that as her disability progresses, she finds new adaptations for her leisure pursuits. Another woman with genetic bone disease stated, "Cause I really don't consider it a disability. It's just made me have to modify some of the things, the way I do them."

Other women, however, did not define themselves by their disability. Generally they described their role, citing either their family if they were married and/or had children or they described their jobs if they were employed. A typical example was given by one woman with chronic fatigue syndrome who began her interview by saying, "I am 32 years old. I am a wonderful person [laughter]. I am a mom with two kids ages almost three and almost six." One woman described herself in this way:

Well, I'm a 48 year old Caucasian woman. I'm currently divorced. I'm the mother of two sons . . . I've lived in [name of city] for 14 years and was born and raised in Baltimore, Maryland. I've been working for [name of organization] for five years . . . I work 25 hours a week. Ah, I do a lot of walking regularly for exercise and my hobbies are listening to music and vegetable gardening and bird watching. And, ah, I guess one unusual thing about me is that I have rheumatoid arthritis which I have had since my second child was born which translates into 20 years.

The data suggested that the degree to which a physical disability was viewed as central to one's functional self-identity was likely to influence social and leisure outcomes. Several women concluded that they were more self-perceptive because of their disabilities. One woman with a visual impairment, for example, said:

I think I can do most anything most people can. However, in my job I have always felt that I did not have to be as good as a sighted person, I had to be better. Consequently, I have developed a perfectionist attitude . . . I mean, you know, it's frustrating, it can be very frustrating.

Another woman with a muscular disorder stated, "I stick to things I know I can do, like going on [short] walks."

Despite the limitations potentially imposed by a disability, leisure appeared to have a positive influence on self-perception. Several of the women remarked how leisure was useful to them. One woman with a muscular disorder said, "It makes you feel good about yourself . . . because you've gotten out." Another woman who uses a wheelchair described leisure as valuable, "When it's something you really want to do, just to be able to have something else to concentrate on, to keep the pressure off, even if it's only for an hour or two." A third woman referred to her leisure by saying, "I will say I want to be all that I can be and be given the opportunity to fail, not to be told I am a failure."

Body-Identity. Body-identity or body image was an issue addressed by all women. It refers to the aspect of self-identity which pertained to attitudes, experiences, and functions involving the physical body. Media representations, the diet and fashion industries, and the general ideology which addresses youth, attractiveness, and anti-fat contribute to women's views about body image (Shaw, 1991). The reality is that bodies, regardless of ability or disability, are exceedingly diverse and constantly changing, although many women are socialized to identify with the perfect body (Wendell, 1989). The society tends to glorify fitness and physical conformity. Because of their disabilities, women with physical disabilities often perceived themselves as further from perfect bodies than women without dis-

abilities. Since physical beauty was valued by society, self-identity could be threatened by disability, as Wright (1983) found and as the women in this study identified. One woman with arthritis said:

Any woman with a deformity is self-conscious. We are all critical in judging our own bodies. You assume that others are judging you in the same way. You have to not let that keep you from participating and hope that others will be able to accept it.

One way that body image influenced the women's leisure related to what they perceived themselves physically able to do. For example, one woman with Charcot-Marie-Tooth syndrome said, "I always had sort of an athletic kind of mind, and a body that wouldn't follow it, that was unable to keep up." Later in the interview she said that she wanted to do more physical activity but she could not because of muscle weakness and fatigue, "I sometimes tell people that I was just given the wrong body. There was a mistake made somewhere, and I got somebody else's body. I get, don't really get angry, but I think I would do a lot more [sans the disability]." Another woman with polio had a similar response, "My physical limitation is that my body simply cannot do what my mind would imagine doing . . . I have a soul that dances like Tina Turner but I, my body can't." The women with disabilities interviewed indicated that it was often difficult to look "together" and not like a "crip" and to discover or maintain an identity that suggested that one's body is lovely as it is.

Some of the women with physical disabilities seemed to have an approach/avoidance response to their bodies that also affected their leisure. They were aware that their lives were housed in the body, but sometimes they rejected the body that did not function or appear in the way that they wanted. For example, one 50 year-old woman with obesity and burn scars stated,

"I love to dance . . . I don't go now because I feel like everybody's looking at me." Similarly, a woman with rheumatoid arthritis remarked:

I know I have made choices that kept me from doing leisurely things because I didn't want to expose my [deformed] feet. I sit on the beach and bury my feet rather than make others look at them. It impacts my leisure.

Related to leisure, physical activity was seen more often as therapy than as leisure. The women with disabilities, in general, did not experience their bodies in a physical, vibrant way that athletes and people in control of their bodies experience. While some women felt forced to engage in activity to maintain what physical abilities they had, others were "forced" to abandon active leisure and recreation pursuits and substitute more passive activities.

The image that the women described of their bodies differed greatly depending on the disability and how "visible" it was. The less physically disabled that an individual appeared, the easier it was to feel good about her body. And yet, several women expressed resentment at having to explain why they might "look" normal but be unable to function with the control that they wished. For example, a married woman with chronic fatigue syndrome stated:

Ah, and that's where one of the drawbacks of having the disease is that, I mean it's good to be able to go out and fit into the world a little bit here and there and just look normal. But at the same time, it makes it harder for other people to understand that you have that much pain.

Gender-Identity. Gender-identity was another part of self-identity that related to the fundamental sense of one's femaleness and an acceptance of one's gender as a social

psychological construct that paralleled one's biological sex (Deaux & Major, 1990). Gender-identity is usually acquired early in life, but can differ from person to person. It also may be marked by flexibility, fluidity, and variability that changes over time and with circumstances. Many of the women with disabilities, however, perceived that their femininity or femaleness was not always noticed by others.

The women with physical disabilities generally did not indicate that femininity had much to do with their leisure. Femininity was, however, important to them. Similar to the quote that provided the introduction for this paper, a single woman with a muscular disorder stated:

I think it's [femininity] not real important, but I think it is important. People get all fixed up and you're walking around in clunky old braces and wish you could wear high heels. You go somewhere and you're lugging around crutches. It makes you feel not so feminine. It ruins it.

A parallel also existed between the time it took for feminine and time for leisure. One married woman with multiple sclerosis described:

I can't go to extremes . . . like I can't be concerned about you know, my hair being done up exactly so that it looks perfect. I have to make things very simple and easy . . . I got it all cut off and this is what you call wash, comb, and dry. Ah, you don't worry about your make-up . . . Except for things like Saturday night. Tomorrow night I'll put make-up on to go out. Ah, as far as the way I dress, I have to have clothes that are easy to put on, ah, they're not always the most fashionable things. . . I can't wear heels but that's because of the MS and my balance and my not being able to walk.

A divorced working woman with arthritis remarked, "I have a considerable amount of feelings of femininity in spite of the disability. But I feel less feminine because of the disability. I can't "pull off" the feminine image as well as others with shoes, hands, etc."

Sexuality also played a role in understanding gender-identity. Even though many women with disabilities are not affected in their abilities to be married and be mothers (Cole, 1988), several women in this study felt limited by the way their gender-identity was perceived in relation to the social stigmas of society. The role of sexuality was not easy for the women interviewed to discuss.

For single heterosexual women with disabilities, the issue of dating men was frequently mentioned. In a sense, dating was considered a "leisure" activity. One single woman with cerebral palsy explained:

I feel that uh, men, men are kind of scared to meet me anyway, but a physical disability really frightens them off, as I see it. And uh, especially a person with a speech impairment and one, you know, who has fits and who shakes sometimes, you know. It's hard for them to deal with it.

A 38-year old single woman with a muscular disorder said:

I think females without disabilities are more likely to find somebody they can date, can go out with, and get married and have a normal life and have kids than a female with a disability. Some guys will see a female with a disability and they may say, oh gee, you know she's a nice person but she can't do this or she can't do that, so I don't want to get to know her that well.

Role-identity. Self-identity specifically through role-identity related to the gender

socialization and the roles that females in society were expected to fulfill. The traditional roles for women are to be nurturing, supportive, and reproductive. Today many women with and without disabilities also fill roles in the workplace.

A dilemma women with physical disabilities sometimes encountered, however, related to their need to be helped and nurtured. A married woman with two grown children and rheumatoid arthritis lamented:

And you really feel you know, you feel like sometimes you feel like useless and helpless, but yet, I had so much pride I hated to ask anybody to do anything for me. And that's not good, you know, and even though my family is great, you know . . . it's not easy to get someone to help you out.

Related to this notion was the idea that it was important to take care of others so they would not feel uncomfortable. An example of the nurturing role that one woman felt she needed to fill was when one of the researchers shook her hand when they met for the interview. The interviewee grimaced because of the pain, but said she endured it because it would be socially inappropriate if the two had not shook hands.

The impact of the economy, a discriminating society, and negative self-image on women with disabilities often contributes to a feeling of rolelessness in society, according to Fine & Asch (1981). Several women identified the desire merely to have "normal" roles in their lives. A woman with chronic fatigue syndrome, for example, stated, "The thing I look forward to in life . . . I'd love for things to get back to normal and to be able to have some kind of job and . . . a routine that I could . . . live with."

The women with disabilities reacted in different ways to role-identity. Being deprived of traditional gender roles by one's disability, however, was seen as a relief by a

couple women. A 40-year old professional woman with arthritis said:

. . . if I had not developed arthritis wouldn't I probably be married at this point in life and the answer is probably yes. And I would probably have kids and probably be more normal in many ways than I am [she laughs] but I think there is also an awful lot of stress that I've been able to divert from my life or simply not face, that a lot of non-handicapped or women without disabilities haven't been able to . . . a lot of societal pressures. . . . In a way, my arthritis is an excuse . . . I also don't have a whole lot of wrinkles and whole lot of gray hair for somebody my age. . . . I don't want to be uh, jailed by society.

Conclusions

Exploring the experience of women with physical disabilities can create new meanings in understanding self-identity and leisure. The process has been one of discovering, recognizing, and creating patterns where the identity of women with physical disabilities and leisure experience have taken on an emerging perspective.

The women in this study acknowledged self-identity as a component with which they struggled. Although they did not usually relate self-identity directly to leisure, the implications of self-identity to the meaning of leisure were often apparent. Self-perception, body-identity, gender-identity, and role-identity had direct and indirect ramifications for leisure. The potential for leisure seemed to offer possibilities to help women come to terms with bodies that departed from the cultural norm of acceptability and attractiveness (Fine & Asch, 1988). Disability was usually a greater definition of self than was being female, as Fine and Asch (1988) suggested, but in the case of

women with physical disabilities, gender provided a collaborative definer for women's lives.

The psychosocial impact of disability on self-identity and leisure depended on the nature of the disability, extent to which the woman had ascribed to traditional roles, and the reactions of others as social stigma. Disability seemed to have the most severe negative influence on leisure when it disrupted a woman's actual or perceived abilities to perform important societal roles and when a situation was created where desire to participate was not equal to one's ability to participate. The sense of rolelessness as it related to being female and having some physical limitations due to the disability created a major obstacle for women in relation to leisure.

The women in this study were in various stages of recognition of the meaning of their disabilities and the potential for leisure. Self-identity as related to disability and leisure varied greatly among the women and was clearly a dynamic, and not a fixed, situation. The women with physical disabilities varied in their self-identity and how they coped and adjusted to their disabilities. Because of their disabilities, some of the women had emerged into a new self-perception, body-identity, gender-identity, and/or role-identity. Understanding a bit more about leisure and self-identity for women provided a way to address the concerns and needs of women with physical disabilities in community and clinical settings. By exploring the self-identity of women with physical disabilities, it was possible to learn more about the meanings and importance of leisure.

Implications for Practice

If the leisure lives of women with physical disabilities are to be enhanced, "not just a wheelchair, not just a woman" must be kept in mind in understanding how gender

and disability interact. A number of ideas merit consideration. Women with disabilities face many experiences in their lives that are disempowering, like the disability itself and their own self-identities. Having elements of freedom and choice within leisure can lead to empowerment (Henderson et al., 1989). Empowerment is to have or gain some positive sense of control over oneself and one's life opportunities. It implies the ability to take action and improve one's personal and social environment. Empowerment for women with disabilities may mean to be able to provide care for oneself, emotional stability, and a positive self-concept (Chesler & Chesney, 1988) as well as have increased choice and freedom in leisure. Choice and freedom would likely be enhanced if women had increased leisure opportunities from which to choose that related to their personal interests as well as their physical abilities.

Kriegsman and Bregman (1985) suggested that people who have contact with women with disabilities can be helpful in a number of ways. They can provide ways that women with disabilities can share with others so they do not feel so isolated. People in helping positions can acknowledge that gender-identity and sexuality are important regardless of one's physical abilities. Helping individuals set new goals and learn new problem solving strategies related to any aspect of life, including leisure, can lead to empowerment and enhanced positive self-identities.

All leisure choices are not disability-determined, but the context of the disability coupled with self-identity related to the dimensions of self-perception, body-identity, gender-identity, and role-identity greatly influences those choices. The severity of a leisure handicap due to disability can be increased or diminished by the environmental conditions and self-identity that an individual experiences. For example, learning to accept body image anew (Frank, 1988), may

do as much as anything to help a woman with a physical disability learn to enjoy her potential for leisure.

The impact of self-identity also has some direct implications for therapeutic recreation specialists as well as community recreation providers. The first consideration in working with women with physical disabilities is sensitivity to issues like body-identity and gender-identity which are extremely salient for many women. Henderson, Bedini, and Bialeschki (1993) noted that therapeutic recreation specialists ought to examine their own beliefs about the nature of gender and disability before they can facilitate leisure education for others. Although the data suggested women with disabilities have similar leisure interests as women without disabilities, the feelings that one has about oneself and one's body cannot be discounted in any situation. Being female and having a disability are cumulative constraints to leisure that need to be addressed, but each person must be treated in an individual way.

Secondly, therapeutic recreation professionals might consider how opportunities are created and used to encourage an individual's acceptance of her body through recreation therapy activities. Through working with women with disabilities, problem solving techniques can be applied to make decisions about both active and quiet leisure activities. In addition, more than just wheelchair basketball and track and field events must be provided to meet the diverse interests of women with disabilities.

Third, reinforcement is needed to help women to define who they are and to develop gender-identities aside from obvious disability identities. This reinforcement can be accomplished through values clarification and through leisure education in both clinical and community environments. Leisure education will need to address more than leisure values, activity skills, and resources, however. Focusing on aspects of body-identity and role-identity for women with physical disabilities is necessary to

make leisure more useful as a therapy for rehabilitation and personal growth. Tying these issues of self-identity into assertiveness training programs could be particularly useful.

Fourth, for those individuals moving from a hospital setting to their community, successful reintegration can be fostered in a number of ways. If self-perception or body-identity poses a barrier for active participation within one's community, both clinical and community recreation programs must work together to help individuals facilitate a smooth transition. Cooperative programming is needed to help women with disabilities identify and access physically safe and satisfying leisure opportunities. Although community integration is a common goal in all therapeutic recreation programs, particular attention to issues of psychological and physical safety is warranted for women with physical disabilities. In addition, community programmers may want to consider "transition" or "support" groups for women who are referred from facilities. These groups may function best as "all women" groups if issues like gender-identity and role-identity are addressed.

Self-identity and leisure behavior are complicated phenomena which require further study. In continuing to build on the emerging body of knowledge, we may want to heed what a young woman with cerebral palsy said about this research:

Well, I hope this interview helps . . . for women, you know, I hope that it can educate some of the people who are disabled who feel like that there's no life in this life . . . being physically disabled doesn't stop you from being alive.

To provide opportunities for a quality of life through leisure for women with physical disabilities, leisure cannot be viewed apart from self-identity and the traditional and changing roles of women in society. Being

female and having a disability, being "not just a wheelchair, not just a woman," are fluctuating traits that must be re-examined in providing opportunities for personal empowerment through leisure.

References

- Asch, A., & Fine, M. (1988). Introduction: Beyond pedestals. In M. Fine & A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture and politics* (pp. 1-38). Philadelphia: Temple University Press.
- Bandura, M. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191-215.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Brown, L. S. (1990). The meaning of a multicultural perspective for theory-building in feminist therapy. *Women & Therapy*, 9(3), 1-21.
- Chesler, M. A., & Chesney, B. K. (1988). Self help groups: Empowerment attitudes and behaviors of disabled or chronically ill persons. In H. E. Yaker, (Ed.), *Attitudes toward persons with disabilities* (pp. 230-245). New York: Springer Publishing Company.
- Cole, S. S. (1988). Women, sexuality, and disabilities. *Women & Therapy*, 7, 277-294.
- Deaux, K., & Major, B. (1990). The social-psychological model of gender. In D. L. Rhode (Ed.), *Theoretical perspectives on sexual difference*, (pp. 89-99). New Haven, CT: Yale University Press.
- Deegan, M. J., & Brooks, N. A. (1985). Introduction-Women and disability: The double handicap. In M. J. Deegan & N. A. Brooks (Eds.), *Women and disability: The double handicap*, (pp. 6-22). New Brunswick: Transaction Books.
- Deem, R. (1986). *All work and no play? The sociology of women and leisure*. Milton Keynes, England: Open University Press.
- Fine, M., & Asch, A. (1981). Disabled women: Sexism without a pedestal. *Journal of Sociology and Social Work*, 8(2), 233-248.
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Social Issues*, 44(1), 3-21.
- Frank, G. (1988). On embodiment: A case study of congenital limb deficiency in American culture. In M. Fine & A. Asch, (Eds.), *Women with disabilities: Essays in psychology, culture and politics* (pp. 41-71). Philadelphia: Temple University Press.
- Freysinger, V. J., & Flannery, D. (1992). Women's leisure: Affiliation, self-determination, empowerment, and resistance? *Loisir & Societe/Society & Leisure*, 15(1), 303-321.
- Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing, Co.
- Green, E., Hebron, S., & Woodward, D. (1990). *Women's leisure, what leisure?* London: MacMillan Education LTD.
- Henderson, K. A. (1990). The meaning of leisure for women: An integrative review of the research. *Journal of Leisure Research*, 22(3), 228-243.
- Henderson, K. A. (1991). *Dimensions of choice: A qualitative approach to recreation, parks, and leisure research*. College Park, PA: Venture Publishing, Inc.
- Henderson, K. A., Bedini, L. A., & Bialeschki, M. D. (1993). Feminism and the client-therapist relationship: Implications for therapeutic recreation. *Therapeutic Recreation Journal*, 27(1), 33-43.
- Henderson, K. A., & Bialeschki, M. D. (1991). A sense of entitlement to leisure as constraint and empowerment for women. *Leisure Sciences*, 13, 51-65.
- Henderson, K. A., Bialeschki, M. D., Shaw, S. M., & Freysinger, V. J. (1989). *A leisure of one's own*. State College, PA: Venture Publishing, Inc.
- Howe, C. Z. (1993). Naturalistic research design: An interrelated approach to data collection and analysis. In M. J. Malkin & C. Z. Howe (Eds.), *Research in therapeutic recreation* (pp. 235-254). State College, PA: Venture Publishing, Inc.
- Kriegsman, K. H., & Bregman, S. (1985, December). Women with disabilities at midlife. *Rehabilitation Counseling Bulletin*, pp. 112-122.
- Lenskyj, H. (1989). *Toward a new interpretation of female values in school and community sport*. Paper presented to Society for the Sociology of Sport Conference. Washington, D.C.

- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- McCormick, B. (1991). Self-experience as leisure constraint: The case of Alcoholics Anonymous. *Journal of Leisure Research*, 23(4), 345-362.
- Mudrick, N. (1988). Disabled women and public policies for income support. In M. Fine & A. Asch, (Eds.). *Women with disabilities. Essays in psychology, culture and politics* (pp. 245-268). Philadelphia: Temple University Press.
- Samdahl, D. M. (1987). A symbolic interactionist model of leisure: Theory and empirical support. *Leisure Sciences*, 10, 27-39.
- Shaw, S. M. (1991). Body image among adolescent women: The role of sport and physically active leisure. *Journal of Applied Recreation Research*, 16(4), 349-367.
- Traustadottir, R. (1992). Obstacles to equality: The double discrimination of women with disabilities. *Journal of Leisurability*, 19(2), 4-9.
- Wearing, B. (1991). Leisure and women's identity: Conformity or individuality? *Loisir & Societe/Society & Leisure*, 14(2), 575-586.
- Weinberg, N. (1988). Another perspective: Attitudes of persons with disabilities. In H. E. Yunker, (Ed.), *Attitudes toward persons with disabilities* (pp. 141-153). New York: Springer Publishing Company.
- Wendell, S. (1989). Toward a feminist theory of disability. *Hypatia*, 4(2), 104-124.
- Whitson, D., & Macintosh, D. (1989). Gender and power: Explanations of gender inequalities in Canadian National Sports Organizations. *International Review for Sociology of Sport*, 24(2), 137-150.
- Wright, B. A. (1983). *Physical disability—A psychosocial approach* (second edition). NY: Harper and Row, Publishers.